

ORIGINAL ARTICLE

Knowledge, Attitude and Practice Patterns Regarding Eye Donation, Eye Banking and Corneal Transplant in a Tertiary Care Hospital*Vijayamahantesh. M. Bijapur¹, Vallabha K.^{1*}**¹Department of Ophthalmology, BLDEU's Shri B M Patil Medical College, Vijayapura-586103 (Karnataka) India***Abstract:**

Background: Corneal diseases constitute a significant cause of visual impairment and blindness in the developing world. Corneal transplantation remains a major treatment option for restoring sight among those suffering from corneal blindness. The number of corneal transplants done is far less than the actual requirement in India. This is largely due to the inadequate numbers of corneas collected. Factors affecting procurement of corneas and public attitude towards eye donation has recently received much attention in our country. Tertiary care hospitals with ICUs and trauma centers have high morbidity rates and cornea procurement rates can be higher with readily available patient investigation, previous treatment and other data to consider suitability of cornea for transplantation. *Aims and Objectives:* To assess awareness regarding eye donation, eye banking and corneal transplant among patient attendants in ICU, Casualty and Eye Out Patient Department in a Tertiary Care Hospital. *Materials and Methods:* The prospective analysis from August 2014 to May 2015 of 1100 proforma of relatives found in waiting areas of ICU, casualty and eye out Patient Department were asked to fill a pretested questionnaire containing questions on demographic details, awareness regarding eye donation, intention to donate eyes, reasons for donating or pledging and not, and sources of information. The data collected was studied and

analyzed. *Results:* Of the 1100 participants, 570 were males and 530 females. 1052 people (95.6%) knew about eye donation, 406 (36.9%) people knew that eye to be collected within 6-8 hours of death, 829 subjects (75.36%) knew that one eye donation benefits two blind people. The contact place for donation was known to only 413 subjects (37.55%). 483 subjects (43.9%) agreed to donate eye of their relative in case of demise. Newspaper was most common source of information for 1005 participants (91.4%), followed by television (76.4%), doctors (68.6%), Pamphlets (59.2%), Friends (57.8%), Radio (52.7%), posters (51.3%), nursing and other staff (47.8%) and others (25.5%). Of those 888 willing to donate 95.2% (845 subjects) would be doing as a noble deed, 745 (83.9%) for pleasure to help blind, 690 (77.7%) were motivated by the idea of giving vision to someone after their death. Of 212 unwilling, 178 participants (83.9%) disliked the idea of body being tampered with and 124 participants (58.5%) had objection by family members. *Conclusion:* The reasons for not donating need to be considered while creating awareness about eye donation in the community. Knowledge, attitude and practice in the context of eye donation may not complement each other and need to be addressed to bring about a change in patterns observed.

Keywords: Eye Donation, Eye Banking, Corneal Transplant, Willing and Unwilling.

Introduction

We see the world and receive more than 90 % of our knowledge through eyes. Cornea is the most valuable part of eye. It constitutes the outer coat of the eye ball. It covers the inner contents of the eye ball, protects them from noxious insult by microbial agent and other environmental trauma. Even then if things do go wrong, it lends itself to surgical replacement by which visual acuity can be restored?

Corneal diseases constitute a significant cause of visual impairment and blindness in the developing world. With 7.8 million blind people in India, the country accounts for 20 per cent of the 39 million blind population across the globe, of which 1 percent is on account of corneal blindness [1].

Corneal transplantation remains a major treatment option for restoring sight among those suffering from corneal blindness. The number of corneal transplants done is far less than the actual requirement in India. This is largely due to the inadequate numbers of corneas collected. Dandona et al 2003 and Krishnaiah et al 2004 concluded that the major causes of corneal blindness include trachoma, corneal ulceration following xerophthalmia due to vitamin A deficiency, ophthalmia neonatorum, use of harmful traditional medicines, onchocerciasis, leprosy and ocular trauma. [2-3].

For the XIth five year plan (2007-12) under the National Program for Control of Blindness (NPCB), the Government of India envisages achieving the goal of elimination of avoidable

blindness in the country by the year 2020 by modification of existing schemes and introduction of new ones [4]. Besides other issues being addressed, corneal blindness is also targeted and eye banking activities are being up-scaled through financial assistance to developing eye banks and eye donation centers.

The Andhra Pradesh Eye Disease Study (APEDS) [5] reported the prevalence of corneal blindness at 0.13% (95% CI: 0.06-0.24), constituting 9% of all blindness. APEDS also suggested a significant burden of corneal blindness in the rural population of Andhra Pradesh, of which 95% was avoidable. Although strategies to prevent corneal blindness are likely to be more cost-effective, visual rehabilitation by corneal transplantation remains a major treatment option for restoring sight in those who already have corneal blindness [5].

Approximately 18.7 million people are blind in India [6] and 1, 90,000 are blind from bilateral corneal disease. Every year another 20,000 join the list [7]. This problem is compounded by a low level of annual procurement of donor eyes which is 18,000 annually as per a report of the National Program for Control of Blindness and Eye Awareness [7].

After the first successful corneal transplantation by Edward Zirm, it has now become the most successful example of organ transplantation. With the understanding of corneal anatomy and physiology especially with regard to corneal endothelium, introduction of microsurgical

technique, advances in corneal preservation, the upcoming of corneal immune suppressive agents, have resulted in a high success rate of corneal grafting.

The late Dr. Muthiah started the very first eye bank in India and he performed the first corneal transplant successfully in 1948 [8]. Even after more than 60 years, patients waiting for corneal transplants constitute a considerable backlog which is growing.

According to the Eye Bank Association of India (EBAI), the current cornea procurement rate in India is 22,000 corneal donations per year. Of these, a significant proportion is unsuitable for transplantation [9]. Based on our current ratio of suitable corneas, we would need 2, 77,000 donations per year to perform 1, 00,000 corneal transplants in a year in India [10].

Shortage of transplantable corneas is common and has been the subject of much attention. There is approximately a 20-fold increase from the donor eyes available now. To enhance the procurement of corneal donations, raising the level of public education on eye donation remains the most important first step [3]. Soliciting for actual eye donation at the time of death is a necessary and accepted practice [10].

It is necessary to gain increase in achievement of actual donations as by suggesting eye donation at the time of death or to relatives of gravely ill or injured patients [10]. Factors affecting procurement of corneas and public attitude towards eye donation has recently received much

attention in our country with support and participation by the government and NGOs [11].

Tertiary care hospitals with ICUs and trauma centers have high morbidity rates and cornea procurement rates can be higher with readily available patient investigation, previous treatment and other data. Cornea can also be collected more easily than from home-death donations, in sterile hospital environs. This study was designed to assess awareness regarding Eye Donation, Eye Banking and Corneal Transplant among patient attendants in ICU, Casualty and Eye Out Patient Department in a Tertiary Care Hospital.

Materials and Methods:

The study was designed as knowledge, attitude and practice study. The study was taken place in the waiting areas of ICUs, casualty and eye outpatient-departments of BLDE University, Shri B M Patil Medical College, Hospital and Research Center, Bijapur, Karnataka, India. It was conducted from 1st August 2014 to 31st May 2015. The study was approved from Institutional Ethics Committee. One thousand and one hundred relatives were chosen as per sample size.

A pretested questionnaire was filled in by relatives found in waiting areas of ICUs, Casualty and Eye OPDs after obtaining informed consent. The questionnaire contained questions on demographic details, awareness regarding eye donation, intention to donate eyes, reasons for donating or pledging and not, and sources of information. The data collected was studied and analyzed by using SPSS software version.

Results:

Out of the 1100 participants, 570 (51.82%) were males and 530 (48.18%) females. Age varied from 25 to 60 years, 645 (58.64%) were between 25 and 40, and remaining 455 (41.36%) subjects older than 40. Of these people, it was observed that out of 1052 participants (95.6%), 554 males and 498 females, knew about eye donation, but that the eyes are to be collected within 6-8 hours of death was known to only 406 (36.9%) participants, in other words >60% did not know what was the ideal time to collect eyes after death, and also that they can be collected despite most existing medical ailments. 264 relatives (24%) found it difficult to discuss the subject in light of the grave medical condition of their patient.

829 subjects (75.36%) knew that one eye donation benefits two blind people. The contact place for donation was known to only 413 subjects (37.55%). The majority of the participants were willing to pledge their eyes or already had, but only about 483 subjects (43.9%) agreed to consider eye donation of their relative patients in case of their demise.

Only 16.4% (180 participants) knew that only the cornea can be donated. 1050 of the participants (95.5%) felt that number of donations should be enhanced, however of those people whose relatives were registered for and awaited donation 346 of the 1100 subjects (31.5%) wanted to look for alternative treatments for regaining vision other than corneal transplantation. (Table 1 and Fig.1)

Table 1: Responses to Questionnaire on Eye Donation (N=1100) (Multiple Responses)

Responses	Males(N=570)	Females (N=530)
Eyes can be donated after death	554 (97.2%)	498(93.9%)
Ideal time for collection is within 6 hours of death	280 (49.1%)	126 (23.8%)
Know an eye bank or EDC	315 (55.3%)	98(18.5%)
Know that one eye donation benefits two blind	453(79.5%)	376 (70.9%)
Know that only the cornea is transplanted	72 (12.6%)	108 (20.4%)
Willing to pledge eyes or already pledged	518 (90.8%)	452 (85.3%)
Willing to donate eyes of their patient	356 (62.5%)	127 (23.9%)
Know of shortage of eye donation in India	526 (92.3%)	524 (98.9%)
Know someone who needs transplant	360 (63.2%)	236 (44.5%)
Know someone who has donated eyes	65 (11.4%)	26 (4.9%)
Know someone who has received a transplant	126(22.1%)	56 (10.6%)

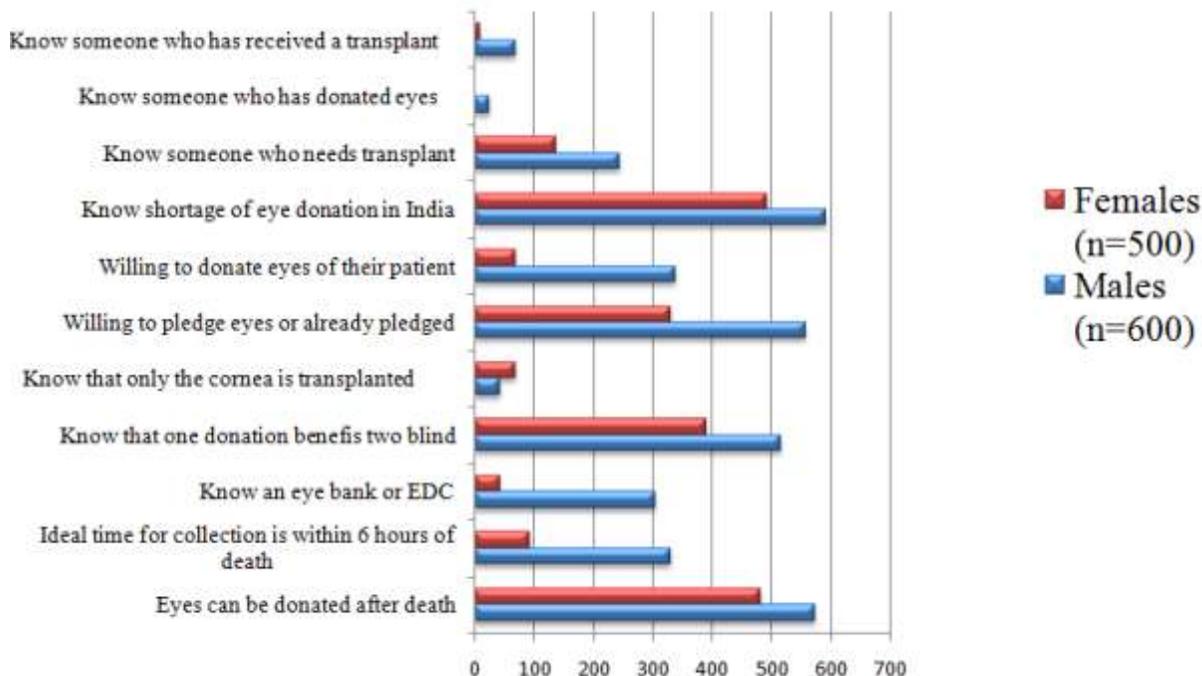


Fig 1: Responses to Questionnaire on Eye Donation (N=1100) (Multiple Responses)

Newspaper was the most common source of information on eye donation for 1005 participants (91.4%), followed by television for 840 (76.4%) and 755 (68.6%) from doctors. 651(59.2%) from

Pamphlets, 636 (57.8%) from Friends, 580 (52.7%) from Radio, 564 (51.3%) from posters, 526 (47.8%) from nursing and other staff, 280 (25.5%) other sources (Table 2 and Fig. 2).

Table 2: Sources of Information on Eye Donation (N=1100) (Multiple Responses)

Sources	Number (N=1100)	Percentage
Newspaper	1005	91.4%
Television	840	76.4%
Posters	564	51.3%
Doctor	755	68.6%
Nursing and other staff	526	47.8%
Radio	580	52.7%
Pamphlets	651	59.2%
Friends	636	57.8%
Others	280	25.5%

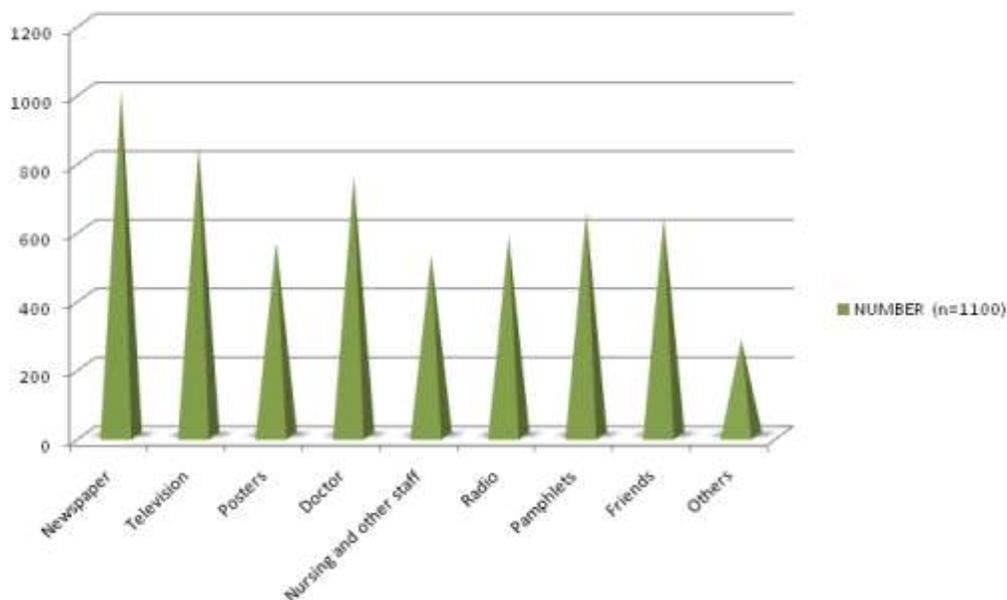


Fig. 2: Sources of Information on Eye Donation (N=1100) (Multiple Responses)

Nobility of the act of eye donation was the main motivational force according to 95.2% (845 subjects) of those willing to pledge their eyes. 690 (77.7%) and 745 (83.9%) were motivated by the idea of giving vision to someone after their death and the pleasure in helping the visually deprived respectively, 530 (59.7%) were influenced by an

article they read, 452 (50.9%) by a lecture they attended poster or a movie they saw. 296 (33.3%) knew someone who has donated eyes, 194 (21.8%) knew someone who has received eyes and 84 (9.5%) without any reason (Table 3 and Fig. 3).

Table 3: Reasons for Willingness for Donating Eyes (N=888) (Multiple Responses)

Reasons	Number	Percentage
Eye donation is a noble deed	845	95.2%
A pleasure to help the blind	745	83.9%
It gives vision when we are gone	690	77.7%
Influenced by an article read on eye donation	530	59.7%
Influenced by a lecture, poster or a movie	452	50.9%
Know someone who has donated eyes	296	33.3%
Know someone who has received eyes	194	21.8%
No reason	84	9.5%

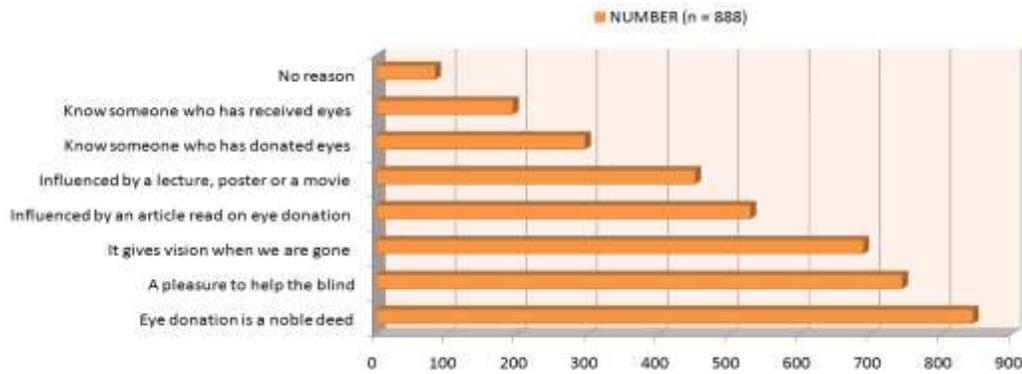


Fig. 3: Reasons for Willingness for Donating Eyes (N=888) (Multiple Responses)

As many of the participants had some relative or friend who was in a critical condition, the subject of eye donation was sensitive and was unwilling. Of 212 unwilling participants 178 participants (83.9%) disliked the idea of body being tampered with and 124 participants (58.5%) had objection

by some family members. 96 (45.3%) were unaware of eye donation, so unsure, 46 (21.7%) people thought that eyes are unsuitable because of age and 35 (16.5%) because of ill health. 24 (11.3%) objected for religious sentiments and 10 (4.7%) without any reason (Table 4 and Fig. 4)

Table 4: Perceived Reasons for Refusing Donations (N=212) (Multiple Responses)

Reasons	Number	Percentage
Dislike idea of body being tampered with	178	83.9%
Objection by family members	124	58.5%
Unaware of eye donation, so unsure	96	45.3%
Unsuitable because of age	46	21.7%
Unsuitable because of ill health	35	16.5%
Religious sentiments	24	11.3%
Others	10	4.7%

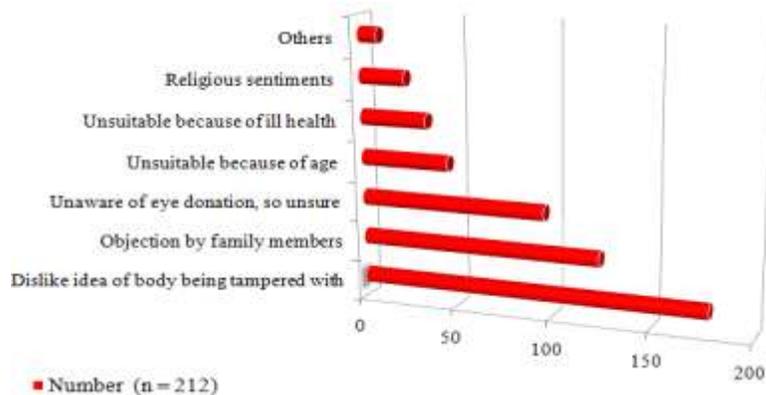


Fig. 4: Perceived Reasons for Refusing Donations (N=212) (Multiple Responses)

Nearly half of the respondents, 574 out of the total 1100 (52.2%) opined that more public awareness should be generated to enhance eye donations. 612 people (55.6%) felt that donors consent should be mandatory and that it should be obtained before death, however according to 285 (25.9%) the consent could be given by the next of kin.

Discussion:

Corneal transplantation offers the potential for sight restoration to those who are blind from corneal diseases. This, however, is dependent on people willing to pledge their eyes for donation, and relatives willing to honor that pledge upon the death of the person. Data from our study suggest that additional efforts are needed to improve awareness of eye donation. In this study, 95.6% of the subjects knew about eye donation awareness ranged from 50.7% to 97% in different studies [12-14, 3]. Information by mass media could be related to the high level of awareness in our study participants.

In our study 406 subjects (36.9%) knew that the ideal time for donation would be within 6 hours of death and only 413 (37.54%) knew of the existing eye bank where they could donate eyes or get any information. Many of the participants (>60%) did not know the appropriate time to collect corneas after death or that they could be donated despite pre-existing medical conditions or advanced age. But the timing of eye donation being important, it may not be ideal to utilize eyes for optical purposes that are donated later than 6 hours after death. A study on medical and nonmedical students has also observed that 79.6% of medical

students knew that eyes can be donated after death and 63.3% knew that it should be done within 6 hours [15].

Although majority were willing to pledge their eyes (888 subjects-80.7%), only 406 subjects (36.9%) were willing to donate eyes of their relatives who might be seriously ill. In a study among medical students, 87.8% of the respondents were willing to be eye donors [15]. Another study in an urban population 73.8% were aware of eye donations and only 44.9% were willing to pledge their eyes [16]. Willingness to donate eyes was less (41.5%) even among relatives of post-mortem cases who were in spite of being aware of eye donation [17].

Mandatory consent for donation expressed before the death of the donor should ideally form the basis for eye donation. However, in the case of unavailability of such consent, consent from adult family members of the deceased donor should be obtained for eye donation. In our study 612 people (55.6%) felt that donors consent should be mandatory and that it should be expressed before death, however according to 285 (25.9%) the consent could be given by the next of kin. In a study done on the responses of relatives of post-mortem cases, it was revealed that out of the potential post-mortem donors, only 44.3% of relatives of such cases gave consent for donation after intensive counseling [18].

That eye donation is a sensitive issue is well exemplified further in our study as 245 people (22.3%) found it difficult to discuss the subject at a time their relative was gravely unwell. The prime reasons cited for eye donation were nobility of the

deed; pleasure in helping the blind and the feeling of keeping eyes alive even after death; and articles, posters lectures also did influenced many. On the other hand, displeasure at body tampering, objection by family and unawareness about donation were major factors behind refusals. Similar reasons were also reported in other studies [16, 18].

Enhancing awareness and dispelling myths, and glorifying donation as the supreme gift have no substitute plans for increasing eye donations. Mass media in the form of newspapers, television, radio programs, posters and public shows etc are important sources of information on eye donation. Other studies also found publicity campaigns and the media to be the major sources of information on this issue [3, 17]. Awareness needs to be enhanced to increase uptake of corneal transplant surgeries as 381 of the 1100 subjects (34.6%) have opted for alternative treatment options to increase the vision.

Strategies that have worked well in other parts of the world may be useful here too. For example, in USA, the Presumed Consent Law was introduced in 1975. This concept has legal sanction, where, if the dead person has not registered any objection to donate while alive, consent is presumed and eyes can be removed as required. This legislation has led to a manifold

increase in the availability of corneal tissue. In India we do not yet have such legislation; the government may consider the concept of "presumed consent" to boost eye donations. Such legislation would emphasize the government's commitment to the cause of eye donation. Another area of legislation is the "required request law", wherein it becomes mandatory for all health care staff, institutions coming into contact with bereaved families to make a request for eye donation. This requires legal sanction [19].

Conclusion:

The present study revealed that most of the people were aware about eye donation and most of them were willing to donate their eyes. The major reasons for not donating eyes were lack of awareness which showed that our national programmes for elimination of corneal blindness and eye banking were not effective as they are not creating enough awareness. People had misconceptions in their knowledge about eye donation. Therefore the perceived reasons for not donating eyes need to be considered while creating awareness about eye donation. Knowledge, Attitude and Practice in the context of eye donation do not complement each other and need to be addressed to bring about a change in the behaviour patterns observed.

References

1. WHO, Visual impairment and blindness Fact Sheet N°282 June 2012.
2. Dandona R, Dandona L. Corneal blindness in a southern Indian population: Need for health promotion strategies. *Br J Ophthalmol* 2003; 87:133-41.
3. S Krishnaiah, V Kovai, R Nutheti, Bindiganavale R Shamanna, R Thomas, Gullapalli N Rao. Awareness of eye donation in the rural population of India. *Indian J Ophthalmol* 2004; 52: 1: 73-78.
4. Dandona L, Dandona R, Naduvilath TJ, McCarty CA, Nanda A, Srinivas M, et al. Is current eye- care policy focus almost exclusively on cataract adequate to deal with blindness in India? *Lancet* 1998; 351:1312-6.
5. Dandona L, Dandona R, Srinivas M, Giridhar P, Vilas K, Prasad MN, et al. Blindness in Indian state of Andhra Pradesh. *Invest Ophthalmol Vis Sci.* 2001; 42:908-16.
6. Dandona L, Dandona R, John RK. Estimation of blindness in India from 2000 through 2020: Implications for the blindness control policy. *Natl Med J India.* 2001; 14:327-34.
7. Saini JS, Reddy MK, Jain AK, Ravinder MS, Jhaveria S, Raghuram L. Perspectives in eye banking. *Indian J Ophthalmol.* 1996; 44:47-55.
8. Kannan KA. Eye donation movement in India. *J Indian Med Assoc.* 1999; 97:318-9.
9. Dandona R, Dandona L, Naduvilath TJ, McCarty CA, Rao GN. Awareness of eye donation in an urban population in India. *Aust N Z J Ophthalmol.* 1999; 27:166-9.
10. Saini JS. Realistic targets and strategies in eye banking. *Indian J Ophthalmol.* 1997; 45:141-2.
11. Diamond GA, Michael C, Mussoline JF, D'Amico RA. Obtaining consent for eye donation. *American J Ophthalmol.* 1987; 103:198-203.
12. Priyadarshan B, Srinivasan M, Padmavathi A, Selvam R, Saradha R, Nirmalan PK. Awareness of eye donation in an adult population of southern India. A pilot study. *Indian J Ophthalmol.* 2003; 51:101-4.
13. Singh P, Kumar A, Pandey CM, Chandra H. Level of awareness about transplantation, brain death and cadaveric organ donation in hospital staff in India. *Prog Transplant.* 2002; 12:289-92.
14. Golchet G, Carr J, Harris MG. Why don't we have enough cornea donors? A literature review and survey. *Optometry* 2000; 71:318-28.
15. Dhaliwal U. Enhancing eye donation rates. Training students to be motivators. *Indian J Ophthalmol* 2002; 50:209-12.
16. Dandona R, Dandona L, Naduvilath TJ, McCarty CA, Rao GN. Awareness of eye donation in an urban population in India. *Aust NZ J Ophthalmol* 1999; 27:166-9.
17. Tandon R, Verma K, Vanathi M, Pandey RM, Vajpayee RB. Factors affecting eye donation from post-mortem cases in a tertiary care hospital. *Cornea* 2004; 23:597-601.
18. Phadke KD, Anandh U. Ethics of paid organ donation. *Pediatr Nephrol* 2002; 17:309-11.
19. Farge EJ, Silverman LM, Khan MM, Wilhelmus KR. The impact of state legislation on eye banking. *Arch Ophthalmol* 1994; 112:180-85.

***Author for Correspondence:** Dr. Vallabha K, Aniketan Nursing Home, K.K Nagar, Near BDA Office, Vijayapura-586109, Karnataka, India Email: aniketankv@yahoo.co.in Cell: 09845737131